Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

MAY 13, 2024

CDC's website is being modified to comply with President Trump's Executive Orders.

ME/CFS in Children

WHAT TO KNOW

ME/CFS is often thought of as a disease only in adults. But children can also get ME/CFS. Scientists do not know what causes ME/CFS. There is no cure or approved treatment for the illness. ME/CFS can be challenging for children and those who care for them.

Symptoms

Children and adolescents with ME/CFS have many of the same symptoms as adults. Like adults, their symptoms may appear similar to other illnesses, may come and go and may change over time. However, there are some differences of ME/CFS in children and adolescents. They are:

• Children, especially adolescents, have dizziness and lightheadedness (orthostatic intolerance) more often than adults. It is often the most unbearable symptom and may make other symptoms of ME/CFS worse.

• Sleep problems in young children may show up as a lack of their usual energy. In adolescents, sleep problems may be hard to detect, as sleep cycles change during puberty. Common sleep complaints in this age group include trouble falling or staying asleep, daytime sleepiness and intense or vivid dreams.

• Unlike adults with ME/CFS, children and adolescents with ME/CFS do not usually have muscle and joint pain. Yet headaches and stomach pain may be more common in this age group. Younger children may not be able to describe the pain well.

• In children, particularly in adolescents, ME/CFS is more likely to start after an illness, like the flu or mononucleosis. Sometimes, ME/CFS in children begins gradually.

Diagnosis

There is no test to confirm ME/CFS. A diagnosis of ME/CFS requires at least 6 months of illness. However, children should be seen by a healthcare provider as soon as they become ill. Children should not wait months to see a doctor.

To diagnose ME/CFS, the child's doctor may:

• Ask about medical history, including a review of any medications and recent illnesses.

• Do a thorough physical and mental status examination.

• Order blood, urine or other tests.

Doctors might refer patients to see a specialist, like a neurologist, rheumatologist, or a sleep specialist. These specialists may check for other conditions that can cause similar symptoms and can be treated. Patients can have other conditions and still have ME/CFS. Getting treatment for other conditions might help patients with ME/CFS feel better.

A guide to assessment

To better understand the child's illness, a doctor may ask many questions. Depending on the child's age, the questions might be asked of the child, parent/guardian, or both (together or independently). Questions might include:

• What is the child able to do now? How does it compare to what the child was able to do before?

- How long has the child been ill?
- Does the child feel better after sleeping or resting?
- What makes the child feel worse? What helps them feel better?
- What symptoms keep the child from doing what he/she needs or wants to do?
- Does the child ever feel dizzy or lightheaded? Has the child been falling more often than before?
- Does the child seem to have trouble remembering or focusing on tasks?
- What happens when the child tries to do activities that used to be normal?

Tracking symptoms in a journal can help the child and family remember details they can share during healthcare visits. Keeping track when symptoms get worse can help identify the effect of ME/CFS on daily activities.

Treatment

Managing ME/CFS in children should focus on treating the most disruptive symptoms. Patients, families, and healthcare providers should work together to decide which symptom causes the most problems. They should discuss the possible benefits and harms of treatment plans, including medicines and other therapies. Other strategies, like learning new ways to manage activity, can also be helpful.

Post-Exertional Malaise (PEM)

Post-exertional malaise (PEM) is the worsening of symptoms after even minor physical, mental or emotional exertion. PEM can be addressed by activity management, also called pacing. For children with ME/CFS, the goal of pacing is to balance rest and activity to avoid PEM. Patients need to find their individual limits for mental and physical activity. Then, they need to plan activity and rest to stay within these limits.

Any activity or exercise plan for children with ME/CFS needs to be carefully designed with input from each child or adolescent. While vigorous aerobic exercise is beneficial for many chronic illnesses, patients with ME/CFS do not tolerate such exercise routines. However, it is important that patients with ME/CFS undertake activities that they can tolerate.

It is important to find a balance between doing nothing and lots of activity, which can make symptoms worse. This means a new way of thinking about daily activities. For example, daily chores and school activities may need to be broken down into smaller steps.

Participation in after-school activities as tolerated is important to support social development. This should be considered even if the child is not able to attend school.

Dizziness and lightheadedness (orthostatic intolerance)

Some children and adolescents with ME/CFS have symptoms of orthostatic intolerance. These are made worse by standing or sitting upright and can include:

- Frequent dizziness and lightheadedness.
- Changes in vision (blurred vision, seeing white or black spots).
- Weakness.
- Heartbeat feels too fast or too hard, fluttering, or skipping a beat.

For patients with these symptoms, healthcare providers will check heart rate and blood pressure. They may also refer the patient to a specialist, like a cardiologist or neurologist.

Sleep problems

Good sleep habits are important for all people, including children with ME/CFS. When children follow good habits and still can't sleep, healthcare providers might recommend taking medicine to help with sleep.

Children might continue to feel unrefreshed after sleeping. This can occur even after the medications help them to get a full night of sleep. If so, they should consider seeing a sleep specialist.

Problems concentrating, thinking, and remembering

Children with ME/CFS may have problems paying attention, thinking, remembering, and responding. For instance, it may be hard for children to take notes and listen to their teacher at the same time.

For children with ME/CFS who have concentration problems, some doctors prescribe stimulant medications. These are the same as those typically used to treat Attention-Deficit / Hyperactivity Disorder (ADHD). While stimulants might help improve concentration for some patients with ME/CFS, they may lead to a "push-and-crash" cycle and worsen symptoms. "Push-and-crash" cycles are having a good day but then push to do more than they would normally do. This "doing too much" results in a "crash," and followed by rest and the cycle repeats.

Depression, stress and anxiety

Adjusting to any chronic illness can sometimes lead to symptoms of depression and anxiety. Anxiety in children with ME/CFS is not caused by the illness itself. It can happen because of the changes the child must make to live with the illness. When healthcare providers are concerned about a patient's psychological condition, they may recommend seeing a mental health professional.

Counseling may help to reduce stress and some symptoms of depression and anxiety, like sleep problems and headaches. Some children might benefit from antidepressants and anti-anxiety medications. However, doctors should use caution in prescribing these medications. Some drugs used to treat depression have other effects that might worsen other ME/CFS symptoms and cause side effects.

Some children with ME/CFS might benefit from trying techniques like deep breathing, muscle relaxation, and massage. They may also wish to try movement therapies (like stretching, yoga, and tai chi). These can reduce stress and anxiety and promote a sense of well-being. Treating depression and anxiety can ease mental and emotional distress in some patients. It can be very beneficial but is not a cure for ME/CFS.

Pain

Children with ME/CFS often have headaches and stomach pain. Doctors may want to check for food allergies and vision problems. Gentle massage and heat may relieve pain for some patients. Parents/guardians should always talk to their child's healthcare provider before trying any medication. Doctors may recommend trying over-the-counter pain-relievers, like acetaminophen or ibuprofen.

SOURCES

CONTENT SOURCE:

National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)